From the Perspective of Women

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From my experience as an HIV-positive woman and as a participant in the 076 clinical trial, I have found that the issues pertinent to health care providers are not always the issues at the forefront for HIV-positive women. This is not to say these issues should not be addressed, but they may need to be addressed in a different manner. The clinical and social expectations we have of these women may not be reachable, but supporting these women is paramount in providing the best clinical care we can. Health care providers, including myself, have their own biases when it comes to HIV-positive pregnant women. Providers should not be judgmental about this, but focus on what will help most.

I am privileged and honored to be part of a great support team for HIV-positive women at Johns Hopkins. We have found that it is of great help to connect HIV-positive pregnant women with women who have already been through this experience. It greatly enhances acceptance of the clinical strategies of providers by opening these women up to the fact that they are not the only ones who have had to deal with this, and by connecting them to a community of people who will be there to help them when the clinical staff can't be, for example, when they are having adverse reactions to their medications or when they need help with the children because they are feeling too sick to deal with them. The WIN study has helped show just how many people in the HIV-positive community are willing to help and dedicate their lives to helping others who are positive.

It's important that HIV prevention efforts in this area address the whole community. That is, men and their role in transmission of HIV to infants need to be addressed. It is not only a woman's problem. For example, we have found that offering counseling and testing to men who accompany women to GYN clinics (before the women get pregnant) has been a very successful strategy. The belief that you can't reach low-income African American males is simply not true; I can say that when I have approached these men, I have had a 97% acceptance rate (it's true we use tests other than the blood test).

The hardest-to-reach women are not those who know they are HIV-positive, but the women who get less than optimal prenatal counseling and testing or who can't imagine that they might possibly be infected or could have an infected baby. I would like to see guidance and training for providers who offer HIV counseling and testing because it is not like other STDs.

I would also like to see incorporated into counseling and testing sessions an overview of what is currently happening with HIV. Many women in minority communities feel that, since there is no cure for HIV infection, nothing can be done. We must reach them with the message that there is no reason for total despair and much can be done for them and for their unborn baby.

Programs targeted to HIV-infected pregnant women can be successful as is evidenced by our own program at Johns Hopkins. We have had 100% of our women accept some kind of therapy; some as late as 34 weeks, but most beginning at 14-20 weeks. This is not only because of the efforts of the 5 people working on support, but also because we "employ" others to help us, even if it is just to make a phone call to these women (sometimes the women are more willing to talk on the phone than have a face-to-face interview). Because of our high rates of acceptance of testing and treatment, since 1994 we have had only one baby infected whose mother has come through our program (the mother already had an

herpes infection when she enrolled).
Finally I want to thank this group for the efforts it has made and the progress it has made which gives hope and inspiration to those of us working on the front lines.

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I also want to emphasize the importance of helping HIV-infected pregnant women find others who have faced this situation. I think it would have been helpful to me back in 1990 when I was having to make decisions and deal with the fact that I was a pregnant woman infected with HIV.

It is also important for health care providers to listen to and respect women's desires and choices. Their views, especially their views on their own health condition, need to be taken seriously. I know my health care provider back then would not listen to my wish to take AZT. Today, I would not let my health care provider have the final say.

You need to respect women and their opinions and what they want. You or I may be infuriated with a woman who does not want therapy or a c-section, but it does no good to try to coerce them, because they may just not be ready to hear it. If later, they regret not listening to you, don't take an I-told-you so attitude; just go forward from that point in caring for them. I also think that women have more or, at least, different side effects than men. Women know their own bodies and what they're going through; providers need to respect them and listen to them.

If women are not willing to do what you think is best for them clinically, you should put them in contact with someone who has already been through all this. Again it could be just phone contact; they need not ever meet. But there will always be someone there for them. I think it would have helped me; there is just a sense that you can trust someone more who has been what you're going through.

General discussion: Where there is a conflict between the pediatrician's wishes for the woman and her own wishes, it is best to refer her to a different "messenger;" maybe she will hear the message then.

The community needs to be brought in early in dealing with an HIV-infected woman–there is a lot of stigma surrounding these women. Mentors are often needed for these women; providers may be looking down on them or in other ways not respecting them–women often pick up on this. Also there may be a lot of mistrust of the government and the medical establishment in some of these communities. Bringing a CBO or a non-governmental provider into the situation may help.

Our belief is that the child should not be taken away from the mother unless there is simply no other option for getting the child treated. In that case, the child should be taken into protective services.

Communication with HIV-infected pregnant women is extremely important. Some models that have proved effective are: peer-based counseling and support; programs that empower the woman and others in the community, e.g., to participate in the legislative process; and programs that help the woman to feel good about herself and the future. Stress can be an extremely destructive force in their lives.